

Falls Journal of February 7, 2002, entitled "Family's gift of life leaves enduring bond," by Mary Mahoney.

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FAMILY'S GIFT OF LIFE LEAVES ENDURING
BOND

(By Mary Mahoney)

More than 25 years before his unexpected death, Gary Bradow told his wife Norma that he wanted his organs donated. "I told him that if he went first, I didn't know if I could do it," Norma said from her Fergus Falls home. "Gary told me I could, that I would just know it was right."

But nothing could have prepared Norma for the awful day that Gary died. A malformed artery in his brain caused a fatal stroke in March 1998 at the age of 57. Norma was faced with the one decision she didn't want to make.

"People think of 'harvesting' organs as an awful thing," she said. "But I realized we were farmers; harvesting is a wonderful thing for farmers. And in the case of donating Gary's organs, 'harvesting' was wonderful too."

A man in Wisconsin received a kidney. A 63-year-old widow got another kidney. Two others received his eyes.

And State Rep. Darlene Luther was the recipient of Gary's liver, literally occurring hours before she would have died.

A simple thank-you letter written to Norma six months after the transplant established a bond that couldn't be broken—even after Darlene's death on Jan. 30.

"I don't think of myself as one but as two persons," she wrote, signing only her first name.

With those words, Norma knew she had to connect with this woman who had reached out to her.

"Her letter touched my heart in a way I just can't describe and I immediately called LifeSource and said I had to meet her," Norma said. "It took awhile, but two weeks before Christmas 1998, both of them (Darlene and her husband U.S. Representative Bill Luther) were here."

In the four years since Darlene's transplant, the Bradow family became dear and special friends with the Luthers, visiting often and corresponding frequently. Darlene even flew out to Seattle one day to have lunch with Norma and her daughter Pam, who lives in Seattle, and flew back the same afternoon.

"The bond we had was completely beyond words," Norma said. "She was such a kind and generous lady."

Another twist of fate connected the families as well. Bill, who grew up in a dairy farm near Fergus Falls and has relatives in the area, had briefly known Gary before his death.

"I knew of them and had spoken with Gary before all of this happened," Bill said. "And the odds that my wife would receive a liver transplant from a man from my hometown—it's just amazing the way life can bond people together."

To Darlene, it was a sign that more needed to be done to increase awareness of organ donation. She felt she was the perfect person to educate people about the benefits of organ donation as a state representative, and helped enact legislation providing funding for a mobile education unit for LifeSource, the organ donation procurement organization that helped secure her liver.

"She (Darlene) did such a great amount of work, getting families to talk about organ donation," said LifeSource Public Relations manager Susan Mau Larson. "She was a living statement of the wondrous good provided by organ donation."

The mobile unit is similar to a bookmobile, with displays and kiosks about organ donation. In late December, LifeSource presented a plaque that will hang in the mobile unit, thanking Darlene for all the work she's done for organ procurement.

Last week, a bill passed through the House of Representatives—named in honor of Darlene—making a person's organ donation wishes a binding contract, meaning a family member cannot override the decision. The Senate will begin its process on the bill today, Mau Larson said.

But despite the positive work Darlene provided, tragedy struck the Luthers and the Bradows—once again.

"Darlene called me in late October to let me know she had stomach cancer," Norma said. "The anti-rejection drugs masked the cancer and by the time they found out, it was inoperable."

It was then that the friendship shifted and Norma began helping Darlene the way she had been helped after her husband's death.

"I wrote her weekly notes, little inspirational things to encourage her," she said. "Her inner peace was phenomenal; she was such an inspiration to me and I was trying to help her."

When Bill called Norma the morning after Darlene died, she said the news was heart-wrenching enough. But what came next practically took her breath away.

"Darlene had requested she be buried in Fergus Falls, where she could be near us," Norma said. "I burst into tears when Bill said that."

For Bill and his children Alex and Alicia, it was a natural decision.

"We were so appreciative of those four years Darlene received because of the transplant," Bill said. "The Bradows are part of our family."

He insisted that Norma ride in the lead car during the burial procession and that Gary's family, including his mother, Emma and daughters Tara and Debra, take part in the service held Wednesday afternoon at Oak Grove Cemetery.

"That's what they mean to us," Bill said. "And it's what Darlene would have wanted."

great deal about the disorder. We now know what defects in the gene cause the disease, what protein the gene is supposed to produce, what that protein is supposed to accomplish, and why a shortage of the protein results in the cell death that leads to the disease symptoms. Investigators are increasingly optimistic that they are drawing closer to understanding more fully the causes of Friedrich's ataxia and to developing effective treatments.

At the National Institutes of Health and around the world, clinical trials for Friedrich's ataxia are being conducted on drugs that hold real promise. Intensifying cooperation among organizations supporting the research and the multidisciplinary efforts of thousands of scientists and health care professionals provide powerful evidence of the growing hope and determination to conquer Friedrich's ataxia. There is a growing conviction that treatments can and will be developed for this disease and that the resulting insights will be broadly applicable across a wide range of neurological disorders.

On the third Saturday of May, events will be held across our country to increase public awareness of Friedrich's ataxia and to raise funds to support the research that promises treatments for this disease. I applaud the Friedrich's Ataxia Research Alliance for its contributions to these efforts and ask my colleagues to join me in recognizing May 18, 2002, as Friedrich's Ataxia Awareness Day to show our concern for all those families affected by this disorder and to express our support and encouragement for their efforts to achieve treatments and a cure.

CHILDREN'S HEALTH COVERAGE IMPROVEMENT ACT OF 2002

HON. BOBBY L. RUSH

OF ILLINOIS

IN THE HOUSE OF REPRESENTATIVES

Thursday, May 16, 2002

Mr. RUSH. Mr. Speaker, I rise today to address the plight of low-income uninsured children with the introduction of the Children's Health Coverage, Improvement Act of 2002.

Throughout the United States there are over 11 million uninsured children under the age of nineteen. Over two-thirds of these children live in families with household incomes below 200% of poverty. In my home state of Illinois alone 435,000 children have no insurance, ranking Illinois 24th in the nation in the percentage of uninsured. Over 102,000 of these uninsured children reside in Cook County.

In hope of enrolling those low-income children who are eligible for SCHIP, I am introducing the Children's Health Coverage Improvement Act of 2002 which: Provides \$100 million in grants annually from unspent SCHIP allocations to community-based public or non-profit organizations for the purposes of conducting innovative outreach and enrollment efforts; and It is my hope that through this legislation we can ensure that every low-income child has the health insurance they qualify for and deserve.

FINDING A CURE FOR FRIEDREICH'S ATAXIA

HON. CHRISTOPHER COX

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

Thursday, May 16, 2002

Mr. COX. Mr. Speaker, I rise today to make my colleagues aware of Friedrich's Ataxia Awareness Day, which is recognized each year on the third Saturday in May.

Friedrich's ataxia is a life-shortening neurological disorder that is usually diagnosed in childhood. It causes muscle weakness and loss of coordination in the arms and legs; impairment of vision, hearing and speech; scoliosis, diabetes; and a life-threatening heart condition. Most patients need a wheelchair full-time by their twenties. Life expectancy is reduced to early adulthood. There is currently no effective treatment or cure for Friedrich's ataxia.

Although there is no treatment or cure available, Friedrich's ataxia patients and families have more and more reason for real hope. An extraordinary explosion of research findings has followed the identification of the Friedrich's ataxia gene in 1996. Since that discovery, research scientists have learned a